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Meanings and senses of Hansen's disease for health workers from a Vygotskian perspective: a qualitative study

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Abstract

Background Hansen's disease is an infectious disease with a slow and chronic evolution that can manifest itself through skin lesions, with changes in thermal, painful and tactile sensitivity, and also affect peripheral nerves, causing significant physical disabilities. This study aimed to analyze the meanings and senses for health workers from outpatient services who provide care to people diagnosed with Hansen's disease.

Methods This is an exploratory qualitative study that used the Vygotskian theoretical-methodological framework based on the dimension of historical-dialectic materialism that bases its procedures on the use of meaning cores. The study was carried out in Ribeirão Preto, in the inland state of São Paulo, Brazil. In total, 13 health professionals participated in the study, including two nurses, three physicians, five nursing assistants, a physiotherapist and two social workers.

Results To understand the meanings and senses of Hansen's disease, we take three cores of meaning as a basis: (1) personal, professional and social aspects of health workers and Hansen's disease, the health workers report that their view of what Hansen's disease was based on the understanding that it was an infectious disease that caused deformities, known as "leprosy", and that those affected needed to be isolated; (2) Hansen's disease – neglected, invisible and unknown, the invisibility of Hansen's disease continues to haunt those affected by it, and diagnosis is still late, referring to the marks carried in the history of Hansen's disease that remain today; and (3) challenges and potential in the world of work in the Hansen's disease reference services, the dichotomies, challenges and potential of working with those affected by Hansen's disease are linked to the creation of bonds, love for the profession, religious beliefs and problems related to the lack of resources for the rehabilitation of those affected.

Conclusions The re-elaboration of meaning can occur when professionals are inserted in the world of work. The socially produced senses and meanings surrounding leprosy are related to its invisibility and late diagnosis. Changing the meanings and senses requires mediation and the use of critical active methodologies in health education, with investments from training bodies, social movements and health services.

Keywords Hansen's disease, Health workers, Meanings, Senses, Neglected diseases, Qualitative research

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Background

Hansen's disease is an infectious disease with a slow and chronic evolution that can manifest itself through skin lesions, with changes in thermal, painful and tactile sensitivity, and also affect peripheral nerves, causing significant physical disabilities in those affected [1]. It is an ancient disease that was present in civilizations that are now mainly considered part of the developed countries [2].

Since colonization, Hansen's disease has been present in Brazil. The first healthcare establishments for people affected by Hansen's disease appeared in the seventeenth century. During the 1920s and 1930s, the Brazilian government built hospital-colonies that focused on excluding patients. The people in the hospital-colonies were considered "leprosy sufferers" and they lived in an exclusive and stigmatizing way far from their families and society [3].

Due to the social imaginary of "leprosy" and the "leper", in this context the affected person was seen as an incarnation of evil, being linked to dirt and human misery [3]. The isolationist policy spread throughout Brazil due to consolidation of the construction of hospital-colonies [4].

The lack of knowledge about Hansen's bacillus and the fear and repulsion towards patients triggered preventive measures, not for the sick but for the healthy people who could live freely in society. In this way, the social imaginary and limited scientific knowledge about leprosy's etiology, treatment and prevention supported the isolation policy of the time in Brazil [5, 6].

The historicity involved in "leprosy" and Hansen's disease is embedded in a social, cultural and historical context that is perceived by actions of strong social exclusion and prejudice towards people affected by the disease. An important distinction is highlighted between "leprosy" and Hansen's disease because they are not equivalent and do not correspond to each other in their senses and meanings, being present in different historical and social periods [6].

From this perspective of social and historical construction, Lev Vygotsky, a great scholar of the historical-cultural perspective, states in his writings that in the relationship between Man and society there is a sharing of constant tension of difference, although constituting itself in a mutual way [7]. Thus, Man as a social and singular subject is a synthesis of multiple determinations that, in social relations, constitute his subjectivity; in this way, Man constitutes himself as human in history, in the constant process of objectification and subjectification [8].

Due to concerns and sensitivity in understanding social, political and educational problems, Vygotsky sought to understand how the subject, Man, is inserted

in a given society or culture [9]. In this way, Vygotsky, focusing on the constitution of the subject and subjectivity in procedurality, made it possible to understand this psychological phenomenon. Hansen's disease, like other diseases and illnesses, carries meanings and senses that are socially constructed through sociocultural, economic and political relationships that permeate objective and subjective aspects [10].

The scientific literature presents studies on the understanding and impact of Hansen's disease on the lives of people affected by the disease [10–14] as well as the family impact [15]. The literature has also focused on patients' experiences and meanings in relation to Hansen's disease, therapeutic itineraries, stigma, quality of life and their relationship with health professionals and health systems [16–20].

However, there is a lack of research that focuses on healthcare workers' understanding of the topic, with biological knowledge of the disease and treatment predominating [21] and also stigma on the part of the professionals themselves [22, 23].

According to the World Health Organization (WHO), throughout the world in 2023, around 182,815 new cases of people affected by Hansen's disease were registered, with more than 22,773 new cases recorded in Brazil in the same year [24]. Brazil is the second country in the world in terms of the number of new cases of Hansen's disease, accounting for 93% of cases in the Americas, which classifies Brazil as a priority country for Hansen's disease according to the WHO. During the period from 2013 to 2022, 316,182 cases of Hansen's disease were reported in the country, with a considerable reduction in diagnoses during the period of the Covid-19 pandemic between 2019 and 2022 [25]. The city of Ribeirão Preto has one of the highest detection rates in the state of São Paulo and in the year 2023 the rate reached 24.9 cases per 100,000 inhabitants, a condition considered as very high endemicity according to the evaluative parameters of the WHO [26].

Given the current context in which Hansen's disease is an important public health problem, this study aimed to analyze the meanings and senses for health workers from outpatient reference services who provide care to people diagnosed with Hansen's disease.

Methods

Study design

This is an exploratory qualitative study [27] that used the Vygotskian theoretical-methodological framework [7] based on the dimension of historical-dialectic materialism that centers its procedures on the use of meaning cores [28, 29] guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) [30].

Theoretical-methodological framework

According to the Vygotskian perspective, the system of relationships is formed in the historical-cultural process, through words and also communicative acts in which the meaning is expressed; the meaning makes reference to the affective experiences of the subjects through the relationships that occur in the situations experienced [7]. Thus, in meaning, which comprises a stable system of generalizations, there is also an individual meaning that is re-elaborated in a dialectical way [7, 31]. For Vygotsky [7], it is not possible to identify meanings and senses separately, as both are constructed and reconstructed together, given the complexity of the subject and of social interaction.

Meanings and senses are always in production and are also present in the relationships between health workers and people diagnosed with Hansen's disease. Sometimes these relationships can be guided by a biologicistic-reductionist stigmatizing conception, expressing a power-subordination relationship between the professional and the patient [32].

In this way, Hansen's disease has meanings and senses for those who care and those who are cared for in a complex process that is woven through history, context and culture.

Study setting

This study was carried out in Ribeirão Preto, a large city in the inland state of São Paulo, Brazil, located in an economically active region with 698,642 inhabitants [33]. The two health services included in the research were specialty outpatient services used as a reference for the treatment of people with Hansen's disease in the municipality. During the study period, the treatment was centralized only in the two services that participated in the research. The professional categories that work in the care of people affected by Hansen's Disease in the city are nurses, physicians, nursing technicians, nursing assistants, physiotherapists and social workers.

Participants

The study participants were health workers from two reference services (outpatient services) who worked directly with people affected by Hansen's disease. In total, 13 health professionals participated in the study, including two nurses, three physicians, five nursing assistants, a physiotherapist and two social workers.

Sampling, sample size and non-participation

The inclusion criteria were professionals who had worked for more than a year with people affected by Hansen's disease and who were in professional activity during the

period of data production. Health workers on vacation or who leave during the data production period were excluded from the study, as were those who had less than one year of experience in caring for people with Hansen's disease.

In the study there were four non-participation. One nursing assistant was not eligible to participate in the study because the health worker was on vacation during the period of data production and after the return from vacation the health worker did not have an available date to participate in the study. One nursing technician was on medical leave, one nurse and one nursing technician were not able to participate because they did not have an available date on the work schedule to participate in the study.

The health workers were invited to participate in research in the health service itself through an invitation from the first author, who presented the study objective, risks, benefits and what participation would be like if they accepted. There were no explicit refusals to participate in the study and data production took place between July 2014 and July 2015.

Data production

One of the techniques used to produce data in this research was by interview, using a semi-structured script, with sessions developed by the first author (K.S.S) at a date, time and place chosen by the interviewee. The script contained questions linked to: health workers' prior knowledge of Hansen's disease, even before professional training; how the topic had been addressed during training; how the people who live with the participants perceived their work; how the participants went to work with people diagnosed with Hansen's disease; their significant experiences with people affected by Hansen's disease; and what they understood as health policies related to the topic. The complete semi-structured interview script is provided in Additional File 1.

All the participants chose to carry out the interview in the workplace, with only the participant and the researcher present at the time. An interview was carried out with each participant, lasting 40–60 min. The study participants' speeches were recorded on a digital device, later transcribed in full and analyzed from a Vygotskian perspective.

To guarantee confidentiality, the names of the participants were anonymized, leaving only the profession corresponding to the following acronyms: NA (nursing assistant), N (nurse), P (physician), PT (physiotherapist) and SW (social worker) followed by a sequential number according to the order of the interviews in each professional category.

The field diary was also one of the study's data production tools, which allowed the researcher to make notes regarding feelings, thoughts, reflections and conversations linked to the research topic. In this sense, the writing of the diary was carried out in an analytical way, describing the networks of actions and knowledge that took place in the daily life of the research [34].

Data analysis

The data analysis was conducted by the authors (K.S.S, M.F.C.G. and C.M.F) from Vygotsky's theory [7, 28], historical-cultural-dialectic discussions on understanding the meanings emerge [35]. The steps involved during analysis serve to equip the researcher to delve into the meanings (generalization, foundation and essence of the word) and senses (the experience, concrete and personal dimensions) within a historical-cultural context. Through the speech of the interviewees, the cores of meaning emerged [35].

To prepare the cores of meaning, it was necessary to carry out several exhaustive readings of the material from the interviews. The first stage consists of removing the pre-indicators [29], with the word as the most important source. The pre-indicators are highlighted in bold in the participants' statements.

We then proceeded to the indicators, which are the agglutination of pre-indicators, whether by similarity, complementarity or opposition [24]. The concrete dimension is visible at this stage, to the detriment of empirical vision. The third stage involves the cores of meaning, followed by inter-core analysis [21]: the process of theorizing the research findings by articulating the different parts of the study results.

Ethical aspects

The study was approved by the Research Ethics Committee at the University of São Paulo, Ribeirão Preto College of Nursing (Certificate of Presentation for Ethical Consideration No. 27107114.4.0000.5393 and Report No. 564.235), issued on 21 March 2014 in accordance with the Guidelines and Regulatory Standards for Research with Human Subjects (Resolution No. 466/2012) of the National Health Council of the Brazilian Ministry of Health.

Informed consent was obtained for each participant. All participants were informed about the study objective and how their confidentiality would be protected, as well as their right to withdraw from the study at any time. Those who agreed to participate gave their informed consent. All participants included in this research gave their consent to use only anonymized quotes in this study.

Results

The study participants were predominantly female (92.3%), with the participation of only one man belonging to the medical category (7.7%), which indicates that professions related to care are still carried out predominantly by a female workforce.

The average age of the participants was 45.5 years; one nursing assistant was 65 years old and had been providing assistance to those affected by Hansen's disease for the longest time (38 years). Only one nurse specialized in neglected diseases and one physician specialized in Hansen's disease. The other professionals had specializations in public health, women's health and education, cardiology, infectious diseases and neurology. Only one of the nursing assistants had not completed an undergraduate course.

To understand the meanings and senses of Hansen's disease, we take three cores of meaning as a basis: (1) personal, professional and social aspects of health workers and Hansen's disease; (2) Hansen's disease – neglected, invisible and unknown; and (3) challenges and potential in the world of work in the Hansen's disease reference services.

Personal, professional and social aspects of health workers and Hansen's disease

The starting point was the knowledge and experiences of health workers in relation to Hansen's disease, even before training as a health professional. This is because the subjects are understood as social beings and the social relationships and understandings are reflected in them [9].

The health workers reported that their view of Hansen's disease was based on the understanding that it was an infectious disease that caused deformities, known as leprosy, and that people diagnosed with Hansen's disease needed to be isolated from others:

Before my training, the concept I had was basically that people really have the old disease, which was formerly known as leprosy. (SW-01)

I saw it like everyone else, you know, a disease that catches you, that deforms you, that you have to stay separated. (P-01)

That the general population knows or thinks they know, right. That it is a very contagious disease, that the patient needs to be isolated. These are the notions that I had before studying [...] that the person had to be isolated, there is no cure [...] The person with the disease he suffers physical defor-

mations, these notions, right, common sense. That at that time [...] still had a bit of truth, although there was already a lot of prejudice, but these are notions that are still strong in society today. (P-02)

I didn't know anything about Hansen's disease. I'd heard of it, but not under the name Hansen's disease. More like leprosy. I heard a lot about it where they were locked up (leprosarium) at the time. But from parents and relatives, from hearing about it, commenting on it... (NA-03)

It is observed that some interviewees had a relative or someone very close to them with Hansen's disease and such experiences enabled these professionals to remember details. For example, details from the uncle with Hansen's disease about the stigma of the disease, the issue of isolation and the marginalization of those with the disease:

I had cases in the family, I had knowledge about the disease. (P-02)

My uncle... We had very common contact with him, practically, for a period it was almost daily, because we lived very close, but everything was separate, I remember everything was separate. (P-01)

My great-grandmother had Hansen's disease, so I knew a little about the stigma of the disease, because she ended up being admitted to the leprosarium, a hospital that took care of Hansen's disease, she ended up staying away from her grandfather, she was looked after by the uncles, by the father, so there was this kind of sad story, I had heard about it, my mother always said it. (P-03)

I remember that in the old days, before I entered the health field, I knew someone who was very close to the family of my grandparents, I remember this prejudice, that they said that we weren't supposed to stay, fine, we went there, but we weren't supposed to stay for long periods in the person's house. (NA-04)

During healthcare workers' academic training, there is very little or no content related to Hansen's disease, so they often continue to hold the perceptions they held before entering the university.

Look, ah... health issues as a whole are just brushstrokes, not specifically this or that, regardless of whether it's Hansen's disease, tuberculosis, HIV (human immunodeficiency virus), no. What I remember, there was only psychiatry material. (SW-02)

We don't have much focus on a segment of social services, for example, health, or social assistance, we sometimes have lectures, some things, on some subjects in these areas, but specifically Hansen's disease I never had it. (SW-01)

Even in my training, I think the approach to Hansen's disease was very deficient. I had contact during the university and even so it was an insufficient contact during the undergraduate course. (PT-01)

I do not remember! So, I'll be very honest, I don't think I even saw this (Hansen's disease) in university. After I graduated from university I thought this (Hansen's disease) didn't exist anymore. (N-01)

Hansen's disease – neglected, invisible and unknown

A nursing assistant who has been working in an outpatient service for three years described that, in general, the population undergoing treatment has some unfavorable social and economic characteristics:

These are people who don't have much education, poor housing conditions, large families, father and mother, four or five children. They're just like that. I didn't notice, during that time I also didn't notice, more educated people, more oriented people, with better conditions, who are undergoing treatment for Hansen's disease. (NA-01)

In their day-to-day work, health workers see firsthand how actions related to Hansen's disease are neglected and, like many, still question the existence of cases:

Hansen's disease is not valued, even here for me to develop nursing care for Hansen's disease, people asked me, but why? But they don't even have cases... Of course there are! Those who know. If I sit back and do nothing there won't be any cases. So, it is very neglected by us health professionals, by society. (N-02)

I'm so discouraged by health policies in general, with the Hansen's disease policies too, I think we should work more on prevention (...) And it's such an old disease.... It was reported in the Bible that talks about Hansen's disease as "leprosy"; it's already two thousand years old, [...] to this day and there are still so many cases, right, it's not possible. There should have been some control, some effective measures by the policy makers... I would have expected the public system to be more efficient in my opinion. (SW-02)

I see it (Hansen's disease policies) as very flawed. The health policy on paper... On paper, it's almost perfect, right? The reality is flawed.... Because people don't know... So the health policy that should start with education but it doesn't exist. It starts with it. Patient care is flawed. (P-01)

The invisibility of Hansen's disease continues to generate serious consequences for people affected by the disease with late diagnosis, as is clear in the following statement:

We have many cases that come to us already advanced, without anyone even seeing the patient, without any health professional who has provided assistance. (P-02)

The marks imprinted on the history of Hansen's disease remain to this day, as can be seen in the speech of the physiotherapist:

Firstly, he (the patient) doesn't know what Hansen's disease is because he still remembers the nomenclature given to Hansen's disease. And another says: "Wow, but does this still exist?", and we know that people still have prejudice, even those who have (patients)... Some people say, but what? You are not afraid? It's quite complicated. (PT-01)

Challenges and potential in the world of work in the Hansen's disease reference services

One physician expresses feelings of love for the profession, respect, patience, qualified listening and also reports how personal issues (religious beliefs) interfere with the image she has of people with Hansen's disease:

So, it's difficult to talk because the patients are very dear [...] I, I have a lot of love for the Hansen's disease patients, so much so that I get emotional talking about it, you know, it's not about the money, it's not about the salary [...] I have a lot of love, I see patients like this, they are very special patients, I am very religious, you know, each disease has its own face, the Hansen's disease patient has the face of a good person in mine head, of course it has its exceptions. (P-03)

This physician also likens becoming ill with Hansen's disease to a game of bad luck, with the person affected by Hansen's disease being the unlucky one:

That's how I see it, a person who wins the lotto is, on the contrary, drawn for bad luck. Because it is a disease that most of the patients I have here they have many, many complications, they are not simple cases like that. (P-01)

The difficulties of working in the Hansen's Disease Control Program are related to material resources, as one nursing assistant points out:

There are patients who need splint, things like that, right? We see with the municipality... But, sometimes, the city hall does not comply with this proposal. How are you going to promise the patient?! So, you park in a few moments. (NA-02)

Now, when you can't get the patient to comply, it's very, very difficult... for us. You feel powerless, so no matter how many ways you try to reason with the patient... to follow the treatment... you can't... There's always a limit, right? And there are patients who you always come up against that limit, you know? And there are patients that, unfortunately, we can't reach at all. (NA-05)

The only physiotherapist in Hansen's Disease Control Program carries out assessments of physical disabilities but notices the difficulty in agreements between the public health system and universities:

The difficulty is that we have an agreement with the universities. Then June, January, December arrives, the universities go on vacation, students go on vacation. So, they stop treating the neurological patient, those patients who already have sequelae also have difficulty maintaining it. You cannot stay with this patient forever, he needs to learn to take care of himself, to have a caregiver. (PT-01)

Discussion

In the first core of meaning, entitled "Personal, professional and social aspects of health workers and Hansen's disease", it is highlighted that the interviewees had meanings related to Hansen's disease before professional training, in which some experienced the disease in their own family environment. These meanings were linked to contagious disease, and situations in which patients should be separated from society, focused on "leprosy" and the "leper".

In the social imagination of a given time in which the magical-religious vision predominated, fatalism/karma is revealed: everything that belonged to the "leper" could be a means of contamination, which prevented people from approaching the patient. In this context, ways of identifying the patient were used, such as the use of a coin, which was typical of patients who lived in isolation, with one side featuring the hospice known as "Lazarus" [36].

There are also scientific discourses that influence the construction of the social imaginary. In the case of the social imaginary about Hansen's disease, during the nineteenth and twentieth centuries the science, which was strongly biomedical in her origin, presented as a guideline for prophylaxis and treatment of the disease, the need to separate people affected by Hansen's disease from the social contexts, including their families, the fact that interfered with the establishment of family ties and relationships [10, 22].

The literature understands that this imaginary about contagion crosses the meanings of what Hansen's disease is, even with the technical-scientific discourse in the opposite movement of deconstruction. This deconstruction movement is known from the historical-cultural perspective as resignification [13, 22, 32].

Using Vygotskian reflection, it is understood that the constitution of the subject occurs through social and historical experience and relationships with other subjects: through intersubjectivity. Thus, the meaning of leprosy and Hansen's disease has been constructed in a historical-cultural way through the experiences of these subjects at a temporal and social level. Therefore, these relationships are not always explicit and they deserve to be investigated for greater understanding of the processes of meaning [9–12].

The construction of meanings takes place on a daily basis and training plays a fundamental role in providing updated scientific knowledge, promoting the reframing of everyday concepts present culturally [37]. This process of resignification involves a back-and-forth movement covering subjective and objective forms. The history of humanity has been characterized by this process of subjective appropriation of reality, in the form of ideals, knowledge, images, etc. and in the creation of objectifications (products generated from these ideals or their transformation) [38].

A study carried out in the Brazilian Northeast region evaluated the knowledge of university students regarding Hansen's disease. The level of knowledge measured was considered unsatisfactory for students studying nutrition, pharmacy and dentistry. The study points to a reflection regarding the knowledge that has been offered to students and the very high level of misinformation about the disease [39]. This corroborates a study carried out in Colombia that sought to explore the perceptions and experiences of health professionals about the delay in diagnosing Hansen's disease, the authors also identified gaps in relation to in-depth knowledge about Hansen's disease [13].

Much of what is learned throughout people's lives ends up being maintained, even after professional training. The historical-cultural theory itself states that learning

occurs everywhere [7]. This leads to the question, highlighted by Vygotsky, about the existence of spontaneous and scientific concepts. Spontaneous concepts are created in the family group, friendship groups, religious communities and among others who are significant in the individual's life. Other scientific knowledge is acquired from work (school and university) and the media.

In relation to the second core of meaning, entitled "Hansen's disease – neglected, invisible and unknown", it is observed in the health workers' statements how Hansen's disease has been neglected, invisible and unknown in terms of the production of meanings and senses.

Changing meanings and senses requires mediation and the use of active and critical methodologies in health education, with investments from training bodies, social movements and health services [37].

Hansen's disease is no longer a public health problem in the United States and Europe. However, in Brazil it still remains as a serious public health problem [40, 41]. Hansen's disease integrates the list of neglected diseases that are closely related to the vulnerability of certain communities and the maintenance of social inequality [41].

Neglected tropical diseases affect the lives of more than one billion people, representing one-sixth of the world's population [42]. Also known as neglected infectious diseases (NID), they have common characteristics: they are associated with poverty and loss of productivity; they affect populations that are vulnerable; most do not spread widely; they cause stigma and discrimination; they have an important impact on morbidity and mortality; they are neglected by research, especially by the pharmaceutical industry; and they can be controlled, avoided and possibly eliminated by employing effective and relatively low-cost solutions [43, 44]. This social complexity around the NID produces meanings and senses both for the people affected and for the health professionals who work directly with these illnesses.

The Sustainable Development Goals (SDGs) in target 03 good health and well-being aims to ensure healthy lives and promote well-being for all at all ages. The target 3.3 is ensured by 2030, end the epidemics of AIDS (Acquired Immunodeficiency Syndrome), tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases. In this sense, in order to achieve the goal of ending the epidemics of neglected tropical diseases by 2030, which includes leprosy, health policies need to be strengthened, taking into account health work and the relevant implications of care processes involving patients, health services and professionals working to care for people affected by leprosy [45].

The physical marks resulting from Hansen's disease affect women's lives, contributing to the maintenance of stigma (and the meanings they carry) and interfering with the tasks performed in everyday life [12]. According to the interpretation of the professionals' statements, Hansen's disease is also invisible to users of Brazil's unified health system (SUS), who arrive for care without understanding the disease or even linking it to Hansen's disease. Research that corroborates the results of this study indicates that these beliefs have a strong relationship with social representations surrounding Hansen's disease, interfering in the diagnosis, treatment and cure of the disease [46].

The attempt to compulsorily isolate the patient was a way of making Hansen's disease invisible, like forgotten people in the world [47]. In the process of stigmatization of Hansen's disease there are socio-historical contexts: initially it was linked to body aesthetics (deformations) and later to the segregation of people affected by leprosy, always linked to issues of impurities [6, 22].

New knowledge regarding Hansen's disease can combat social stigma, and its reframing leads to a consequent transformation in reality [48] that contributes to the improvement of health services and the quality of life of people affected by Hansen's disease.

Vygotskian theory states that psychological processes, external relations and the organism are connected through meanings [8]; in this way, people affected by Hansen's disease, with all the issues of vulnerability, need health workers to perform a role of resignification around diagnosis, treatment and acceptance. Hansen's disease, still present today, may be a sign that the manuals and medicines that reflect health policies are just instruments available to reach the goal of cure, and the entire process towards this end must involve understanding the meanings and senses [49].

The challenges and potential in working with people affected by Hansen's disease, according to the results presented by the third core of meaning, are linked to: the creation of bonds: love for the profession; religious beliefs such as charitable vision; problems related to a lack of resource materials; and agreements established by the municipality for the rehabilitation of people diagnosed with Hansen's disease.

Creating a bond is one of the guiding principles of care in the health-disease process. The process of forming a bond is not easy and is therefore a challenge for health professionals. The bond can be an important enhancer in the construction of meanings and senses. Collet et al. [50] attest that, there is often a trivialization of suffering, feelings and singularities, both of health workers and of users of the health services themselves. The relationship

becomes superficial, creating difficulties in creating bonds and developing care [51].

Brazil has developed the National Humanization Policy (NHP) in its health system, with "welcoming" as one of its guidelines, consisting of identifying what others bring as health needs [52]. It is built collectively as a result of analysis of the work processes, with a focus on building relationships of trust, commitment and bonds between actors [52, 53]. Qualified listening by health workers to users/subjects is one of the main means that allows an assessment of vulnerability, severity and risk.

Brolezzi [54] presents the concept of empathy as something that seeks to explain human manifestations/actions regarding knowledge of others: their ideals, ideas and feelings. It also outlines that Vygotsky already described empathy when he presented the notion of the meaning of imagination and used the German term *Einfühlung* (understood as "feeling within", "feeling in"). Thus, Vygotsky discusses imagination, stating that it becomes a means of expanding the individual's experience because, based on someone else's narration or description, he/she can imagine what he/she has not seen, what he/she has not directly experienced in his/her personal experience. The person is not restricted to the circle and narrow limits of their own experience, but can venture beyond them, assimilating, with the help of imagination, the historical or social experience of others [7].

This expansion of experiences occurs after interaction and relationships with others, through the creation of bonds. The creation of bonds does not happen in a single moment, but develops during meetings, in action, in which it is possible to identify the care that people need. During this care process, meanings and senses are produced, as demonstrated by other studies in the area [55].

It is also possible to observe meanings that were exposed in the characterization of the person affected by Hansen's disease that revolved around charity: "feeling of pity", personalized care for "special people" and the "bad luck" they had in being infected by Hansen's bacillus. Seixas and colleagues [56] suggest the importance of health workers collectively analyzing their own work practices, including the meanings attributed to them, to better understand the process of creating bonds with users in the search for relationships that are more symmetrical and singular.

The research participants noticed a certain fragmentation of care, whether due to the difficulty with material resources or the meanings attributed to Hansen's disease, which accentuates the problems experienced by people with Hansen's disease and also affects health professionals. From this perspective, health work should not be seen in a charitable way, in favor of others, but rather as a

right, an exercise in mediation between the health worker and the person affected by Hansen's disease.

There is a lack of certain resources, such as splints, and low availability of physiotherapeutic care, factors that impact the lives of people monitored by the Hansen's disease service. Unfortunately, this situation is a reality in other health services and leads to work overload [57].

This study allows to reflect on professional practices, particularly in Hansen's disease, and on the mediation of meanings and senses that occur in the process of structuring health care. The health workers themselves play an important role in (re)signification in the process of diagnosis, treatment and acceptance through the articulation of socially constructed concepts with scientific concepts.

Conclusions

It is clear that the meanings and senses present in the workers' discourses are the result of an entire socio-historical process that is constantly changing and is not finished. In this way, the health work occurs as work that takes place in the act, in other words, it emerges as work originating in human relations, which thus determines the production of care. Health work builds interactions all the time with instruments, norms, processes, patients and professionals, and in this way new configurations of professional practices are created.

The training of the study participants was described as insufficient for working in the context of Hansen's disease. The cultural-historical perspective sees the educational environment as enhancing spontaneous knowledge and scientific knowledge. This study shows that in the context of training there is a re-signification in the day-to-day work, which happens in the care of patients affected by Hansen's disease.

Hansen's disease and its policies are considered neglected, proving its invisibility, which is related to a lack of knowledge about the disease, especially on the part of health professionals. Listening and dialog are essential tools for accessing the meanings and senses of those affected by Hansen's disease, as long as it is a two-way, socio-constructive relationship.

Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
N	Nurse
NA	Nursing assistant
NHP	National Humanization Policy
NID	Neglected Diseases
P	Physician
PT	Physiotherapist
SUS	Brazil's unified health system
SW	Social worker
WHO	World Health Organization
HIV	Human immunodeficiency virus
SDGs	Sustainable Development Goals
AIDS	Acquired Immunodeficiency Syndrome

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-12083-9>.

Supplementary Material 1. Semi-structured interview script. Description of data: Semi-structured interview script utilized in the data production for the study intitled "Meanings and senses of Hansen's disease for health workers from a Vygotskian perspective: a qualitative study". The script is divided in two sections, in the first section, intitled section A, the socio-demographic characteristics data were collected from the study participants. The section B shows the semi-structured questions utilized in the data production during the study.

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Authors' contributions

K.S.S. and C.M.F. conceived and designed the study; K.S.S. collected data; K.S.S. and C.M.F. analyzed data and interpretation; K.S.S., M.F.C.G., F.L.S., P.N.A-B, P.S.O., M.G., P.B.A. and C.M.F. drafted the article; K.S.S., M.F.C.G., F.L.S., P.N.A-B, P.S.O., M.G., P.B.A. and C.M.F. revised the final version of the manuscript. All authors read and approved the final manuscript.

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Data availability

The datasets generated and analyzed during the current study are not publicly available due to confidentiality and privacy concerns because the data were produced from a small group of health professionals in an inland city in Brazil; however, they are available from the corresponding author on reasonable request.

Declarations

Ethical approval and consent to participate

The study was approved by the Research Ethics Committee at the University of São Paulo, Ribeirão Preto College of Nursing (Certificate of Presentation for Ethical Consideration No. 27107114.4.0000.5393 and Report No. 564.235), issued on 21 March 2014 in accordance with the Guidelines and Regulatory Standards for Research with Human Subjects (Resolution No. 466/2012) of the National Health Council of the Brazilian Ministry of Health. Informed consent was obtained for each participant.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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